

...offering
information and
inspiration to
individuals with
disabilities and
their families as
they direct their
own supports and
services



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Living His Own Life Now

Sean Ashley In *Real Life Choices*

Editors Note: This is the first in a series of interviews with participants in Real Life Choices. We will re-visit Sean and his family as they move forward in Real Life Choices. We invite you to respond, and ask questions.

When Shawn Ashley put her son, Sean, on the DDD waiting list for community residential services, she knew she didn't want any of the pre-packaged services she had seen. "I initially put him on the waiting list because I was advised to do so. I did it, but I never envisioned that he would live in group home or anything like that. I wasn't ready to place him, I just wanted to be sure he would be safe."

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But ready or not, Sean's number on the priority waiting list came up. When Shawn got the call to ask about placement for Sean, she knew it wasn't the right time. "I wasn't ready to see him leave home. We just weren't at that point yet."

Sean, a 2002 graduate of Atlantic County Special Services School district was living at home with his mom and attending a day program at a local non-profit agency. Shawn recalls "He wasn't happy there. He is a loner...he was the youngest person there by far so he didn't have any friends. And it just wasn't a good atmosphere for him. When DDD told us about *Real Life Choices*, I thought, 'here is our chance,' so I pulled him out of the day program to give it a try."

"For us, *Real Life Choices* has been a God-send," says Shawn. "Sean is much happier now and is living his own life."

As with most new programs, there were some challenges, which Shawn met head-on.

"When I was first interviewed by DDD, I didn't really understand what the personal questions were all about. I'm a private person, and I was pretty vague with them – you know, I didn't really let on to the 'real deal' ... I didn't want to describe all the problems he has– some are personal."

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But when DDD came back and described the level of funding they recommended for Sean, Shawn realized the reason for all the questions. She knew she needed to revisit the assessment process.

“I called DDD and explained the problem. DDD had Sean at a level 2 (of need) and he just isn’t that independent. He needs a lot more personal care. I was re-interviewed and gave them a better idea of what he really could and couldn’t do. I had wanted to make him sound more independent than he really is. Now he is a level 3, and that fits him.”

There were a few other challenges getting started, but none of them insurmountable.

“At first, I was told I could pick who ever I wanted to be his staff,” recalls Shawn. “My sister worked for a nursing service caring for other people, but was willing to leave her job to be Sean’s caregiver. It thought it would be perfect.”

But then DDD told Shawn that family members *couldn’t* be hired and paid as staff.

“It didn’t make any sense to me,” says Shawn. “Why would they want me to hire a stranger when I had my sister, who knew Sean, was trained, qualified and who I trusted?” Shawn wrote a letter to DDD and sent a copy to the Governor and “everyone else I could think of.” A decision was made that Shawn could hire her sister to be Sean’s caregiver.

Today, Sean’s aunt spends daytime hours with him, supporting his personal care needs, taking him on outings, visiting, shopping and doing household chores while Shawn is at work.

The support coordinator from Family Links who is helping with Sean’s plan and services, also suggested that they find a male mentor for Sean - “a guy to hang out with and do ‘guy stuff,’” says Shawn.

Again, Shawn found someone in Sean’s life to be part of his plan. A close family friend, Les, who had work

experience in a group home was hired to be Sean’s mentor eight hours a week.

According to his mom, it has been really good for Sean to spend time with a man. “Sean is a big guy who has his opinions. If he doesn’t want to do something, its hard to make him. Les is older and can guide Sean.”

“...Sean is really enjoying life now...”

With Les, Sean gets to do things that he wouldn’t get to do with his mom or aunt. “Les takes Sean to the barber shop for a hair cut, or out bowling, or to the movies,” says Shawn. “Sometimes they go to the gym or down to Atco to the race track.”

Looking ahead, Shawn hopes to see Sean engaged in volunteer work in his community. With direction from the support coordinator, they are trying to reach out to agencies where Sean may be able to volunteer. “I don’t see Sean holding down a 9-5 job anytime. It just wouldn’t suit him. But I do want to get him doing more things that normal people do to help themselves – independent living skills and community skills.”

With funding through Real Life Choices, Shawn was able to create a plan that supports her son and includes people who already know and love him. “Sean is really enjoying life now,” says Shawn. “I see more of a comfort zone for him - he has his own life and he is living it.”

“There were a few problems, but I guess you would expect that with something new. Overall, things have been great.”

“I know things will change as we go – we may need to rewrite this whole thing. But I know we can. With *Real Life Choices*, we can rewrite things as Sean’s needs change.”

ON THE ROAD TO THE INFORMATION YOU NEED:

ON-LINE RESOURCES TO HELP YOU MANAGE AND PLAN IN REAL LIFE CHOICES

by Steve Smith

DDD has partnered with The Family Support Center of New Jersey to offer a Real Life Choices Resource Database available through the Internet. This directory provides families with information about disabilities and disorders as well as gives you insight on agencies that provide services for the particular disability. Many, but not all, of the agencies have been qualified through DDD to provide services and receive payment for those services. Additionally, the agencies are given a platform to creatively market their organization and services to the public.

Individuals can search the database for agencies in several different manners. The search can be done by inputting an agency name or by providing some program information. Consumers can search keywords resulting in a list of agencies that service the particular disorder within the specified region. Narrowing down the region allows for a more direct search. Also, the agency contact information can be translated into a multitude of different languages. Once you have selected a particular subject followed by selection of the agency, you will be transferred to a different website with allows you to translate anything you copy over to the site. (For more information, please contact FSCNJ).

Log on to:
www.fscnj.org/rlc
for

- Resource Data-base
- On-line Family Chats
- Essential Life Planning Tools

Another feature of this resource tool is the online “chat room” for families currently participating in Real Life Choices. This bulletin board/ “chat room” is an opportunity for families to share information or ideas about services and/or resources. It has been described as a family facilitated, online networking forum. The only people with access to the chat room are the families in Real Life Choices.

In addition to the database and the “chat room,” the website offers consumers and their families the Essential Life Plan (EPS), the tool that initiates their journey into Real Life Choices. The ESP is used by individuals with disabilities to plan and direct the supports and services they want. Its basic premise

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is to empower the individual and provide the resource needed to create a solid plan of care for his/her life. This tool is nationally recognized for its efficiency. The database offers a download for the ESP procedure, which families involved in Real Life Choices can use.

For those providers not yet involved with Real Life Choices, the website has an application section which allows for agencies to apply to DDD in order to provide services for consumers seeking self-directed services. Organizations are encouraged to think creatively and maintain flexibility in their application of services by DDD.

The families, DDD and agencies currently involved in Real Life Choices have been very upbeat about the website and more specifically, the resource database. This resources tool is a tremendous benefit to all those journeying down the *Road to Information*.

Editors Note: This is the first in a series of articles provided by staff from the Division of Developmental Disabilities on resources and issues related to Real Life Choices

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